

Disgusting disruptions: Capturing the everyday experience and burden of managing gastrointestinal infections in the home

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Funding information

This work is supported by the National Institute for Health Research Health Protection Research Unit (NIHR HPRU) in Gastrointestinal Infections [IS-HPU-1112-10038] at the University of Liverpool in partnership with Public Health England (PHE), University of East Anglia, University of Oxford and the Institute of Food Research. The views expressed are those of the authors and not necessarily those of the NHS, the National Institute for Health Research, the Department of Health and Social Care and Public Health England.

Abstract

Gastrointestinal (GI) infections exert a significant public health burden in the United Kingdom and the numbers of episodes are increasing. Younger children are considered particularly vulnerable to infection, and can experience 2–3 GI infections episodes per year, with consequences being more severe for more disadvantaged children, who are much more likely to be admitted to hospital. Few qualitative studies have explored the lived experience of GI infection in the community in the UK. The aim of the study reported here was to contribute to addressing this evidence gap, by examining the consequences of GI infection for 'normal' family life. Eighteen mothers with young children who had recently experienced a gastrointestinal infection were recruited from two socioeconomically contrasting neighbourhoods in North West of England. The findings demonstrated that GI infections were particularly disruptive: experienced as disgusting, laborious and stressful and significantly impacted normal family routines. Women felt burdened by the heavy physical and emotional demands of caring for a GI infection, resulting in feelings of isolation and insufficient support in their caring role from male partners. Tensions also arose from interactions with external community organisations, particularly in complying with their regulations on infection which often undermined caregivers knowledge and expertise of what was best for their children. This study challenges assumptions that managing GI infections in the home is unproblematic and experienced by caregivers as a 'minor ailment.' Infection control measures need to incorporate insights gleaned from the day-to-day realities of caring for sick children in the community.

KEYWORDS

children, gastrointestinal infections, lay experiences, qualitative, UK

1 | INTRODUCTION

Gastrointestinal (GI) infections exert a significant public health burden in the United Kingdom, and the numbers of episodes are increasing (Adams et al., 2017). It is estimated that one in four

individuals in the UK experience an episode of GI infection every year (Tam et al., 2012). GI infections result in absences from work and school which can damage earnings and children's education (Rose et al., 2017), as well as leading to primary care consultations totalling approximately one million per annum (Tam et al., 2012).

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The economic and household burden of these infections, for example, is considerable (Adams et al., 2017, 2018; Rose et al., 2017). It not only reduces children's attendance at school or nursery, but causes the caregiver to be absent from work for on average of 5–6 days (Edwards, Bekkevold, & Flem, 2017; Roberts et al., 2003). Younger children are considered particularly vulnerable to infection, and can experience 2–3 GI infections episodes per year (Lorgelly et al., 2008), causing much anxiety for their parents (Lugg, 2014) and disruption to normal family life. Consequences are more severe for more disadvantaged children, who are much more likely to be admitted to hospital (Rose et al., 2017). Despite the extensiveness of GP consultations for GI infections, the burden of infections is largely hidden (Adams et al., 2017), and under-reporting to healthcare services is common due to the often self-limiting nature of the condition.

The latest quantitative evidence in the UK, cited above, tells us what the patterns of infections and consequences are in the population, but not why and how these patterns arise. These questions need qualitative research that is underpinned by theory of the place of lay knowledge and of intervention research. Lay knowledge is pivotal for achieving the goals of public health research in general and in tackling health inequalities in particular. It enriches understanding of health and disease in different communities and can help identify the barriers for implementing more effective preventive and curative care in the real world (Popay & Williams, 1996; Popay, Williams, Thomas, & Gatrell, 1998; Williams, 2004). A recent systematic review of UK qualitative research on GI infections that incorporates an examination of lay knowledge, however, found a scarcity of such studies, and none that looked at inequalities in GI infections (Rotheram, Cooper, Ronzi, Barr, & Whitehead, 2020).

The aim of the study reported here was to contribute to addressing this evidence gap, by examining the lived experiences of GI infection for families with children. It encompassed how families explained the consequences of GI infection for their normal home life, as well as their experiences of trying to follow official infection control measures in practice.

2 | METHODS

2.1 | Research design

A qualitative design was utilised to understand how parents of young children experienced and managed a recent GI infection, using semi-structured interviews with residents of two contrasting socioeconomic communities. The decision to focus on caring for young children was based on existing evidence that children are at higher risk of GI infection and hospitalisation than adults (Armon et al., 2001; Olowokure, et al., 1999).

The decision to study experiences in two socioeconomically contrasting areas was based on theory and empirical evidence from the public health literature that differing social contexts and places in which people live can influence experiences of and caring

What is known on this topic?

- Gastrointestinal infections in the UK are a significant and increasing public health burden.
- Young children are at high risk, particularly disadvantaged children, with consequences of GI infection more severe e.g. hospital admissions.
- Few qualitative studies have explored the lived experience of caring for a child with GI infection at home.

What this study adds

- Mothers experience GI infections as physically revolting and messy - caring requires excessive amounts of physical labour - with little help from male partners which is seen as unfair.
- Interactions with outside organisations over the child's GI infection amplifies caring difficulties.
- Infection control measures must incorporate insights gleaned from the day-to-day realities of caring for sick children in the community.

for ill-health and the generation of health inequalities (Graham & McDermott, 2006; Macintyre, et al., 2002; Popay et al., 2003). Greater understanding of the influence of social context was considered important to inform more effective action on GI infections.

The study was conducted in one town in the North West of England, and with support from the local public health team, socioeconomically contrasting areas were selected from which to recruit participants. The characteristics of the two areas contrasted in their socioeconomic make-up, including Index of Multiple Deprivation; housing and economic inactivity. The areas were similar in their demographic make-up, including urban, population size and age profile, and similar level of ethnic diversity (reflecting the level of ethnic diversity of the town as a whole) and are shown in Table 1.

2.2 | Recruitment and conduct of interviews

2.2.1 | Recruitment

We aimed to recruit parents living in the two selected areas with at least one child under the age of 11 who had experienced a recent episode of diarrhoea and vomiting (D&V). A 'recent' episode was defined as occurring within the last 6 months to facilitate recall of participants' experience. Participants were recruited if they identified themselves as a primary carer.

Invitations to participate were disseminated through flyers and posters at local schools, children's centres, play groups and nurseries. A total of 21 parents who were primary carers were recruited

TABLE 1 Socioeconomic and demographic characteristics of the two study locations

AREA A – relatively advantaged	AREA B – relatively disadvantaged
Urban	Urban
Population of 5,997	Population of 7,378
Amongst the 30% <i>least</i> deprived neighbourhoods in England (IMD)	Amongst the 10% <i>most</i> deprived neighbourhoods in England (IMD)
25% of its population is aged between 0–19	30.1% of its population is between 0–19
Population - White (63%) Indian (20%) Pakistani (12%)	Population - White (53.8%) Indian (10.6%) Pakistani (25.2%)
Social housing (1.3%) Owned (90%) Renting (7%)	Social housing (30%) Owned (39%) Renting (23%)
2% of households 'overcrowded' (i.e. too few rooms)	12% of houses 'overcrowded' (i.e. too few rooms)
Couple with children (33% of households) Lone parent family (6% of households)	Couple with children (24% of households) Lone parent family (13%)
Population economically 'inactive' (15%)	Population economically 'inactive' (32%)
Higher proportion of workers in managerial, professional or technical occupations, compared with the borough as a whole.	Lower proportion of workers in managerial, professional or technical occupations, compared with the borough as a whole.

BOX 1 Interview questions to illicit participants' accounts of:

- Their last experience of their child having a GI infection episode;
- How they coped with the illness at home;
- Whether their caring experience involved any dealings with health or other services outside the home and, if so, what happened;
- Whether the episode had any wider consequences for them or other members of their household (e.g. time off work, nursery or school; spread of infection).
- Where they thought the infection had come from.

and interviewed, 18 of which were entered into this analysis, as explained below.

2.2.2 | Interviews

Semi-structured interviews were carried out by one of the researchers (either RE or AK) in participants' homes, or private spaces provided by the children's centres, in Area A and Area B, between November 2016 and March 2017. Written informed consent was obtained from each participant at the start of the interview and social and demographic information was collected from participants by asking them to self-identify their characteristics from a check list. Interviews lasted around one hour, using a topic guide, and in most cases one or more children were present during the interviews. All interviews were audio recorded with permission and transcribed verbatim.

Interview questions are summarised in Box 1:

2.3 | Ethical approval

Ethics approval was granted by the Lancaster University Ethics Committee (approval letter dated 9th August 2016.) Each participant received £20 for contributing to the research. All names have been changed to provide anonymity and pseudonyms are used throughout the reporting of findings.

2.4 | Participants

A total of 21 participants who identified themselves as the primary carer of the child with the GI infection episode were recruited and interviewed. During the course of the analysis of the interviews, however, three interviews were excluded from further analysis: one because of disruption by the participant's child, leading to an abrupt ending of the interview; a second because it became apparent during further analysis, that the child's primary illness was whooping cough, not GI infection; the third because the participant was the only man who identified as the primary carer, all other participants were women. Theory suggests that lived experiences concerning being a primary carer may differ by gender, and it would not be sound to draw conclusions about gender differences from one interview with one man. The characteristics of the 18 participants who were entered into this analysis are given in Table 2.

2.5 | Data analysis

Initial analytical discussions of the interview data were carried out among all the authors. A preliminary thematic analysis was

TABLE 2 Participant characteristics and pseudonyms

Pseudonyms ^a	Age	M/F	Area (A = relatively advantaged; B = relatively disadvantaged)	Ethnicity	Highest Level of Education	Employment Status	No. of children under 18 living in the household
Nafisa	30	F	A	Asian Pakistani	Higher	Working: Part-time	3
Mishaim	43	F	A	Asian Indian	Secondary	Not in employment	1
Nusrat	36	F	A	Asian Indian	Higher	Working: Part-time	2
Claire	37	F	A	White British	Further	Working: Part-time	2
Naomi	24	F	A	White British	Further	Working: Part-time	2
Hannah	32	F	A	White British	Secondary	Working: Part-time	1
Suraiya	28	F	A	Asian Indian		Not in employment	2
Hajra	33	F	A	Asian Pakistani	Further	Not in employment	3
Kat	36	F	A	White British	Higher	Not in employment	2
Carly	20	F	B	White British	Secondary	Not in employment	1
Mikhaela	23	F	B	White British	Further	Not in employment	1
Sharon	28	F	B	White British	Higher	Working: Part-time	2
Rachel	30	F	B	White British	Higher	Working: Part-time	3
Emma	25	F	B	White British		Not in employment	1
Sadia	28	F	B	Asian Pakistani	Higher	Not in employment	2
Hayley	34	F	B	White British	Secondary	Not in employment	7
Jameela	31	F	B	Asian Pakistani	Higher	Not in employment	4
Mona	31	F	B	Asian Pakistani	Further	Not in employment	3

Note:: The quotes in results section indicate number of children with a number followed by "C"

^aAll names have been changed to provide anonymity to participants..

undertaken by researchers (RE, AK) using ATLAS.ti software and discussed with the wider research team. The transcripts were analysed descriptively and conceptually using emergent codes from the data that related to our original research aims (Miles, Huberman, Huberman, & Huberman, 1994). Further detailed thematic and critical data analysis of all transcripts was carried out by SM, capturing and refining the coding and identifying emergent themes, with ongoing analytical discussions between SM, MW and ML.

Once the emerging themes were identified, the transcripts were additionally scrutinised comparatively (SM, MW) to explore similarities and contrasts by area of residence, employment and ethnicity.

3 | RESULTS

Three main themes emerged from the analyses of the interviews illuminating the experiences of women caring for children with GI infections at home, and the impact on everyday life. The comparative analysis, on the whole, revealed more similarities than contrasts in the experiences of the participants living in differing socioeconomic circumstances and ethnic backgrounds.

The first theme related to the degree of disgust which was experienced in many of the households with this particular disease.

The second theme was the heavy burden of caring and coping that GI infection put on all participants. Some participants expressed resentment that responsibility rested with them to protect the family and manage the infection, even when they were struggling to cope. The third theme was of the caregivers' strained interactions with organisations in the community, (schools, nurseries, healthcare), and common anxieties when trying to comply with the organisations' regulations on infection while doing what they felt was best for their children.

3.1 | Theme 1. GI infections are physically revolting and messy to deal with at home

The first and most striking theme to emerge was the almost universal experience of disgust and physical revulsion triggered by having to care for a child with a GI infection. The nature of the classic symptoms – diarrhoea and vomiting – produced a physical reaction in many of the participants that introduced an added difficulty into their caring. This experience was similar for participants in both areas and by ethnicity.

Gastrointestinal infections were characterised by many participants as revolting and messy with symptoms such as vomiting and diarrhoea. Participants talked of their disgust:

"... it's like an explosion. It's just everywhere. You can't control it. And it's like water. Like yellow and disgusting and it smells" (Naomi, Area A, White, working, 2C).

"[It] stinks doesn't it? It's disgusting. The house literally stank of puke when all three of them were sick... All weekend, just vomit, vomit, vomit" (Hajra, Area A, Asian Pakistani, working, 2C).

"Well, with the diarrhoea it's disgusting. I always gag and I have to cover my face" (Sadia, Area B, Asian Pakistani, not working, 2C).

Participants experienced GI infections as hugely unpleasant due to the significant 'yuck factor' associated with these infections which made them particularly challenging to cope with:

"It was projectile. Every time [son] drank milk he was projectile vomiting everything out. It was going everywhere... Sick everywhere." (Suraiya, Area A, Asian Indian, not working, 2C).

"I was glad to go back to work. Everybody's like 'how's your weekend been?' and I'm like, 'horrendous'! We're just going to forget it ever happened. The house stinks of vomit. Everybody stinks of vomit" (Rachel, Area B, White, working, 3C).

As the caregiver's attention was focussed on dealing with the sick child, the rest of the family were sometimes neglected as the normal ebb and flow of the household suddenly unravelled. This deviation from normal family routines could, however, be both incidental and intentional:

"If one of us are ill, then nobody goes anywhere. Whoever's ill becomes the centre of attention. If the other ones [children] have got stuff where they need to go, it's like right sorry we can't take them. I don't want to say they become second class citizens but they do really, don't they?" (Hayley, Area B, White, not working, 7C).

The risk of other members of the household becoming infected was of concern. Most participants had more than one child living in the household and when participants recounted their experiences of multiple children being sick either at the same time or consecutively, the disgust and disruption were intense:

"So, I think at one time both of them were puking everywhere. What am I supposed to do now? Got no bedsheets. Puked all over them!" (Hajra, Area A, Asian Pakistani, not working, 3C).

When participants did report suffering illness themselves, feelings of being overwhelmed with exhaustion and guilt for not providing routine activities for children were stated:

"I was like really down that week, I was crying on the phone to my mum saying, 'I can't cope.' I was exhausted, so exhausted. I just didn't want to get out of bed in the morning and look after the [twins] ... I also felt guilty because I couldn't do the things I normally do with the [twins] because I just didn't have the energy" (Sharon, Area B, White, working, 2C).

3.2 | Theme 2: Heavy burden and responsibility put on mothers

The second theme to emerge was the heavy burden of extra work that coping with a GI infection entailed, made worse for some by the isolation that the infection imposes and resentment that the responsibility falls on women, rather than their male partners. Again, participants from both areas and different ethnic groups recounted the extra burden of work, isolation and responsibility involved. While GI infections are not generally life-threatening, they can be dramatic and require a great deal of attention and effort. Much of the physical labour - cleaning up sickness and diarrhoea - fell to women:

"You're constantly washing. It's a whole load of cleaning, isn't it? [Son] did it once here [on floor] then I went to lift him up and take him to the bath and he did it all up the stairs. So that left me with three things to clean. The floor, the stairs and himself" (Suraiya, Area A, Asian Indian, not working, 2C).

Several participants expressed how coping with the infection raised feelings of ambivalence towards the child:

"I stayed at home. It were frustrating because obviously, I was stuck in the house. He [son] wanted to cling to me all the time and that got to me because I couldn't breathe. He was doing it morning til night" (Emma, Area B, White, not working, 1C).

"Well, with the diarrhoea it's disgusting. I do go, 'Arrgh, Euugh!' My eldest, he'll be like, 'I'm sorry, Mummy. But Mum, I'm not well.' I'm like, 'Mm, yeah, but you've got diarrhoea and Mummy can't take it.' [But] when you've got your own [children] you've got no choice. You have to get on with it. ... It can be quite difficult actually" (Sadia, Area B, Asian Pakistani, not working, 2C).

For most participants in this study caring for a sick child was viewed as the mother's responsibility and this experience was largely similar for participants in both areas and in all ethnic groups:

"When they're ill they want me and when your children are ill, I'd rather be at home with them" (Nafisa, Area A, Asian Pakistani, working, 3C).

For women who were not working, and who had more than one child, the responsibility for taking care of the children and the increased domestic labour was largely borne by them:

"I couldn't get on with my daily routine and I had so much work, you know clothes and things especially when [son] was vomiting so much. You'd think how am I going to get through these clothes and everything? Carpets and everything, even if it's like a bit [of vomit], it takes ages to take off" (Mishaim, Area A, Asian Indian, not working, 1C).

The highly infectious nature of GI infections meant that maintaining high levels of cleanliness and hygiene in the home was also seen as part of the mother's responsibility to protect her family. As the domestic labour intensified many women wanted active support and involvement in housework from their partners. This was not always forthcoming:

"...he can't seem to clean up any simple bit of sick...I don't understand it. So I were tired. Angry at him for not cleaning up the sick. Angry at him for not being tired. I'd say 'make a brew' [tea], and he'll go, 'Yeah, in a minute.' [I'd say:] 'What do you mean in a minute? You've not done nothing, do something!' I could have overreacted cos I were tired, but again, he should clean up a bit of sick" (Hayley, Area B, White, not working, 7C).

"we're short now on bedsheets...He'd rather me clean it, than bin it. He'd rather me do that because he doesn't want me to spend money getting more bedsheets if it's only puke. 'It can go in the washing machine, can't it?' I'm like, 'yeh, but why don't YOU do it?' (Hajra, Area A, Asian Pakistani, not working, 3C).

"Oh no, my husband doesn't help, you know. No, it's me on my own. He doesn't do nothing. Lazy" (Sadia, Area B, Asian Pakistani, not working, 2C).

Frustration was expressed about the inequality in domestic work associated with managing the GI infection. This served to create, for some participants, extra strain in an already fractious and disrupted household. And there were limited examples of extra support being extended willingly or proactively:

"I didn't feel [supported]. He [partner] was ill at the same time. I felt like I was the one that just had to get

on with it and I had to remind him that I'm also ill. I know he couldn't help being ill, but he could have still sucked it up and dealt with it a little bit more. But men don't" (Rachel, Area B, White, working, 3C).

"You just feel down. I think you're not happy, if they're not happy. You don't feel like eating, if they're not. It's just the whole environment. But if I am fed up, I just tell my husband 'you do it now, I'm tired.' I think he needs to do a bit more" (Nusrat, Area A, Asian Pakistani, working, 2C).

Another factor was the isolating nature of the illness. Women spoke of being restricted to the home space during the illness, to aid recovery from the illness, but also to avoid the possibility of spreading the infection. For some, the experience lasted for several days. This seclusion was highlighted not only through disrupted routines but through a definite sense of confinement and social isolation:

"we didn't really do much...we were housebound..." (Nafisa, Area A, Asian Pakistani, working, 3C).

"It's a bit hard to go shopping when your kids are ill. There's so [much] stuff you can't do. Sometimes you can't cook because they don't let you. It's like 'Mum, no. Stay with me for a bit'" (Jameela, Area B, Asian Pakistani, not working, 4C).

"... my boyfriend would leave, you'd see the door shut and you'd think 'oh, I've got to get through this now'. I couldn't take [baby] out and I couldn't get my interaction. You want to speak to another adult. You can go days. I mean the week we were in for, I don't think I spoke for a whole day" (Hannah, Area A, White, working, 1C).

For participants in this study, a GI infection was more difficult to deal with compared to other 'common' childhood infections. The findings suggest, however, that women that felt they *had* to cope with the increased physical and emotional demands, as well as the associated isolation of providing care, often with little support. They simply had to get on with it.

3.3 | Theme 3: Caregivers experienced strained interactions with community health and educational services

The third theme emerged from accounts of dealing with external agencies – whether nurseries, schools or health services. Participants encountered problems in navigating the official restrictions in the outside world concerning children who had a GI infection. An added strain for those who were working was having to deal

with workplaces and time-off to care for a sick child. The latter affected participants in the more affluent Area A, as a higher proportion of participants were employed in that area. It also affected the White participants more, for the same reason.

Whilst attending to the burden of GI infections in the household, participants also had to negotiate and navigate dealing with external organisations, complying with multiple 'rules', adding to the strain experienced. During a GI infection, admittance to formal public spaces, such as schools and nurseries is discouraged for 48 hr beyond the last episode of vomiting and diarrhoea to reduce onward infection transmission. This effectively insists that caregivers isolate their child/ren (and by extension themselves) for that duration. Participants reported varying degrees of understanding and compliance with these rules:

"We rang the school to [say] that she wouldn't be in on the Friday cos she was feeling sick. They were like, yeah, that's completely understandable. Send her back when she's feeling better" (Nafisa, Area A, Asian Pakistani, working, 3C).

For others, the rule was not in question but there was ambiguity around the exclusionary timeframe. These uncertainties were demonstrated both by participants who were in paid work, and those at home:

"..the rules are, if the child's sick you're supposed to keep them off for 24 to 48 hours. It varies on the school but I know some children have been sick and then they're in school the next day" (Hayley, Area B, White, not working, 7C).

"I just said to them [school], she's my daughter and I'll know whether she's well enough to come to school or not... If she's got a tummy bug or if she's got diarrhoea, or if she's vomiting... then that child should stay at home. Why should I send her to school?" (Hajra, Area A, Asian Pakistani, not working, 3C).

Others queried where the prime responsibility lay for ensuring compliance with these rules:

"I think, to be honest, it's the school's fault. If they'd sent these messages out previously, other parents would have been aware of the 48 hour rule and they wouldn't be sending them [children] in" (Mona, Area B, Asian Pakistani, not working, 3C).

For the women who were currently in work (White British in both Area A & Area B), the consequences of GI infections and the disruption to everyday routines were felt acutely, in terms of the emotional strain and added stress levels, as well as loss of earnings:

"[When I had to take time off work] it's worrying because I don't get any sick pay, I don't really get holiday pay. It has a big impact. I had to take two days off work because I was ill and they [children] were ill. So we all stayed home. Then my partner had to take the Friday off work because I was ill...so he's like £60 down on a day's work, so we both lost out by about £200" (Sharon, Area B, White, working, 2C).

"I did have a bit of a bout with them [employer]. They were like, 'right you won't get paid.' And I had a barney and I said, 'I could have phoned in sick', I said, 'I've not had a day off sick all year.' We had to split it. I had three days off and my husband had two." (Claire, Area A, White, working, 2C).

In addition to juggling multiple demands and developing strategies to cope, some participants sought professional health advice and reassurance for their children with a GI infection. A healthcare diagnosis provided certainty that the condition was not life-threatening, but it was not always easy to obtain or entirely reassuring:

"I'd wake up in the morning and I'd just pray that he'd be better... It lasted a week and I called [the doctor] twice. They probably just thought - 'oh, overactive mother panicking for no reason.' But on the internet, it says, if your child has it for more than two days you should contact your GP. So, when I did contact them, they weren't bothered. They said - 'you know if they're drinking, just let them be'... I think it would have been nice for someone to go, 'don't worry, he'll be fine' " (Hannah, Area A, White, working, 1C).

GP surgeries often discourage people with symptoms of GI infections from attending the surgery in person. Arranging an appointment with a GP was reported as difficult and time consuming, inducing feelings of apprehension, and frustration:

"I feel like they just shrug me off - 'Oh, it's mild, just let it pass'" (Naomi, Area A, White, working, 2C).

There were contrasting accounts where participants received the reassurance from a GP, and this provided a sense of relief, reducing feelings of anxiety:

"..my GP, he's fantastic. My mind's put at rest and then we just crack on with it and just deal with it when you know it's not anything really serious... just seeing them helps, ... cos not everyone's GP is as good as that" (Claire, Area A, White, working, 2C).

For participants with more than one child, their experience of previous childhood illnesses and understandings around what to do meant

that they relied upon on their own knowledge for managing the GI infection, mindful too, that accessing primary care was not always easy:

"I knew what I was doing. I've had enough experience before... I don't see the point of seeking medical help and wasting their time. It's not petty but you know, something small like that. The GP is actually really helpful...but it's a bit hard to get an appointment" (Sadia, Area B, Asian Pakistani, not working, 2C).

"Generally, I don't run to my doctors as soon as anything happens. I usually wait for a few days to see how they get along. If [son] was dehydrated or any other factors then I'd be contacting my doctor...it was a tummy bug and I didn't feel it was life-threatening. Also, our doctors are not very easy to get an appointment at" (Suraiya, Area A, Asian Indian, not working, 2C).

Coping with competing domestic and public demands around caregiving expectations and responsibilities suggests that women are shouldering much of the burden of managing GI infections, often invisibly, whilst trying to navigate ambiguities around 'best practice' when dealing with organisations in the community.

4 | DISCUSSION

This qualitative study reveals the lived experience of women caring for a child with a GI infection and the consequences for normal family life. We have identified aspects of the experience that, if not unique to GI infection, certainly set it apart as particularly challenging for parents attempting to care for a sick child at home. The first relates to the nature of the classic symptoms of GI infection. A physical reaction of revulsion by the mothers to their child's vomiting and diarrhoea was common and took considerable effort to overcome. This was a reaction not normally encountered when caring for other common childhood illnesses at home and made even the typically short period of the illness more difficult to deal with for women. We have found no other UK studies that identify this aspect of caring for GI infections in childhood.

The second insight is the excessive amount of hard physical labour that these symptoms of GI infection caused for the women, again rarely encountered to the same degree in the care of other common childhood illnesses. Participants found the extra cleaning, washing, disposal of waste and disinfection to keep other members of the family safe, exhausting. Added to this, the isolation that the infection necessitated meant that some of the mothers lacked support from outside when they felt they needed it most. This finding adds to the very sparse literature of qualitative studies in high income countries on managing GI infection in the home. A Canadian study investigating the impact of GI infections on the child's and carer's quality of life found significant negative effects on sleep, appetite and activities

for the child, as well as substantial emotional and physical burdens for the carer (Johnston et al., 2013). A British study of the management of paediatric gastroenteritis at home and within primary care found a high and varied burden on families, including consequences such as time off work, hyper-vigilance to reduce the transmission of illness, emotional, physical and financial burdens (Lugg, 2014).

Within the household, some women in our study recounted a lack of help from their male partners in coping with the vomiting and diarrhoea, a situation which was experienced as unfair and frustrating when they were exhausted. A gendered division of caring such as this is commonly found in the UK in relation to many forms of health and social care provided by families. British Social Attitudes in 2013 found that women reported spending on average 23 hr each week on caring for family members, while men reported 10 hr per week (Park, Bryson, Clery, Curtice, & Phillips, 2013). Most women in the survey considered that the division of labour in the home was unjust because of doing "more than her fair share" (Park et al., 2013). Qualitative studies of mothers of young children and the home management of health and illness more generally (not specifically GI infections) have revealed that women felt particularly responsible for the health and well-being of their children, who were seen as vulnerable and in need of protection (Lupton, 2012, 2013; Power & Hall, 2018). The theory is that this view is partly influenced by societal discourses "of good health as controllable, good health as the outcome of good management and mothers as responsible for promoting and managing their children's health" (Lupton, 2013). A quantitative study in the US found that perceptions of responsibility for housework and childcare among couples were in line with traditional gender roles (women doing most of the childcare tasks, apart from discipline, regardless of which partner had the higher earnings) (Doan & Quadlin, 2019).

Third, there were specific tensions and contradictions arising from the mothers' interactions with external organisations, during and after the episode of GI infection. In some instances, health and education services in the community inadvertently undermined carers' knowledge and expertise through conflicting and contradictory information and practices, contributing further to the often isolating nature of managing a GI infection in the home. From the literature, such tensions risk undermining valuable lay knowledge and expertise, while at the same time weakening the effectiveness of interventions and services which aim to support parents in caring for and promoting health (Cunningham-Burley, et al., 2006; Popay et al., 1998).

Our study also sought to explore mothers' experiences of caring for a child with a GI infection in socioeconomically contrasting communities within a Northern English town. From the comparative analysis, we could discern very few socioeconomic or ethnic differences; instead we found remarkable similarities in terms of experiences of revulsion of the symptoms (theme 1), hard physical labour involved in caring for a GI infection and a gendered division of labour that left women, regardless of SES or ethnicity, with the lion's share of the cleaning and caring work (theme 2). The very nature of a GI infection (disgusting, disruptive, laborious and isolating) seemingly

cut across SES and ethnicity, equalising women's experiences of coping with the consequences of sick children and the attendant increases in physical and emotional demands. An absence of evidence of a contrast is not the same as evidence of no contrast, requiring further research.

5 | LIMITATIONS

A limitation is that the research took place in only one town in the North West of England, though a strength is that participants were recruited who reflected the social and ethnic diversity of the population and gave a richer insight into lived experiences of different groups in the communities. Although the study was designed specifically to compare the experiences of caregivers in two contrasting areas, the analysis was able to identify very few differences, though several similarities. Additions to the study design would be needed to conduct a deeper study of the influence of place and socioeconomic status.

The study was not designed to investigate ethnic inequalities in experience – this would need a wider study with an appropriate sampling strategy. Our recruitment strategy did reflect the ethnic mix of the town's population and of each of the two study areas' populations. We therefore were able to note ethnic similarities and differences in experiences in our analysis and presentation of results, while being cautious about interpreting the ethnic data beyond the scope of the study.

Finally, challenges arose for the researchers because of the necessity of interviewing participants in the presence of their young children, as interviews mostly took place in the participants' homes. Ideally, it would have been an improvement to have two researchers present at each interview, one to conduct the interview and one to occupy the child/children.

6 | CONCLUSIONS

Given the dearth of qualitative research on questions surrounding GI infections in the UK (Rotheram et al., 2020), there is a real gap to be filled to inform the development of more sensitive preventive policies and practices. This study provides new knowledge in revealing how caring for a child with a GI infection at home is particularly challenging because of the nature of the specific symptoms of the disease, which cause revulsion in carers and an exceptional burden of physical labour for the mothers. It exposes the perceived unfairness of the gendered division of labour in caring specifically for GI infection, when the reported squeamishness of male partners to clearing up vomit and diarrhoea puts added burden on women. Participants perceived inconsistency and confusion in the advice they received about keeping children away from community spaces during and after the bout of GI infection. Infection control measures need to incorporate insights gleaned from the day-to-day realities of caring for sick children in the community.

ACKNOWLEDGEMENTS

The authors thank the participants, the public health team for their help selecting socioeconomically contrasting areas from which to focus recruitment, and Dr Friederike Ziegler.

CONFLICT OF INTEREST

No potential conflict of interest was reported by the authors.

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How to cite this article: McGarrol S, Kaley A, Eastham R, Whitehead M, Limmer M. Disgusting disruptions: Capturing the everyday experience and burden of managing gastrointestinal infections in the home. *Health Soc Care Community*. 2020;00:1–10. <https://doi.org/10.1111/hsc.13091>